



NATIONAL SICKLE CELL AWARENESS MONTH, 2022
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BY THE PRESIDENT OF THE UNITED STATES OF AMERICA

A PROCLAMATION

Sickle cell disease (SCD) presents grave health challenges for an estimated 100,000 Americans. For some, it triggers intermittent episodes of pain, difficulty with vision, and serious fatigue. Other survivors experience this disease more acutely -- SCD can cause infections, strokes, and even organ failure. For almost everyone impacted, coping with inherited red blood cell disorders means putting plans on pause, living with excruciating pain, paying for expensive treatments, and hoping for a day when medications and doctor visits no longer interrupt life. During National Sickle Cell Awareness Month, we recognize the perseverance of SCD patients, and we recommit to working with our partners in State and local government, the nonprofit space, and the private sector to develop treatments and cures for this debilitating disease.

Like many rare diseases, SCD affects our population unevenly. Black and Brown Americans are disproportionately affected. About 1 in 13 Black children tests positive for the sickle cell trait, and about 1 in 365 Black Americans develops the disease over the course of their lifetime. Due to persistent systemic inequities in our health care system, these same patients are also often the last to get help. Few specialty clinics are available for SCD treatments, information about detecting this disease is not always widely shared, and pain management can be a challenge due to the intermittent nature of sickle cell crises and persistent racial disparities in pain assessment and treatment. Moreover, there exists no universally effective cure; bone marrow and stem cell transplants have

allowed some people to overcome SCD, but low donor availability and treatment-related complications render these procedures unviable for many patients.

Medical professionals and scientists in my Administration and across our Nation are working to put an end to SCD. The Food and Drug Administration recently approved new drug therapies to help patients manage their pain. Through its "Cure Sickle Cell Initiative," the National Institutes of Health (NIH) is striving to develop safe and effective genetic therapies and exploring applications for machine learning to predict organ function decline in SCD patients. Additionally, the NIH has invited researchers to apply for funding to support large-scale clinical trials on treating SCD pain symptoms. We are closer than ever to finding a cure today for all patients, and I am optimistic about our progress.

Even so, it is still important for Americans to understand the signs of this disease, the risks of inheriting this condition, as well as the various resources available to those who test positive. Most people with the sickle cell trait do not exhibit symptoms, and many are unaware of their potential to carry on this gene. Experts agree that it is important to get tested, especially if you have family members who have been diagnosed with SCD. There are also helpful resources online to learn more about this disease, like the Centers for Disease Control and Prevention's sickle cell information page at cdc.gov/ncbddd/sicklecell/index.html.

As we continue our quest to cure sickle cell disease, let us celebrate the strides our health experts have made in understanding and treating this condition. Let us offer strength to those Americans fighting its effects today and unite in our

mission to enhance the quality of life for those diagnosed with SCD.

NOW, THEREFORE, I, JOSEPH R. BIDEN JR., President of the United States of America, by virtue of the authority vested in me by the Constitution and the laws of the United States, do hereby proclaim September 2022 as National Sickle Cell Awareness Month. I call upon the people of the United States to learn more about the progress we are making to reduce the burden of this disease on our fellow Americans.

IN WITNESS WHEREOF, I have hereunto set my hand this thirty-first day of August, in the year of our Lord two thousand twenty-two, and of the Independence of the United States of America the two hundred and forty-seventh.

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